PATIENT COUNSELING BY COMPUTER*

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Introduction

The basis for our use of the computer in medicine is the thesis that the largest and least utilized provider of health care is the patient. As an example, consider the diabetic patient. If the diabetic patient needed only one injection of insulin a year, I suspect that the professors of endocrinology would be the ones giving it. If an injection were needed every six months, it would be the internist; if every three months, it would be the generalist; and if every two or three weeks, it would be the nurse. But since insulin injections are needed one to three times a day, it is the patient — even the 12-year-old child — who does it and does it well. There are a number of other examples. Renal dialysis, for example, requires a very complex machine. But the person in chronic renal failure learns to use that machine and does it well.

We should try to make it easy for patients to care for themselves when they want to. Our goal with the computer is to help patients help themselves.

I want to start with a brief history of our work with the computer as an interviewing device. This work was done originally with Philip Hicks, Lawrence Van Cura and colleagues at the University of Wisconsin, and it came from our hypothesis that we could program a computer as a model of a physician historian, thereby helping

patients and physicians with medical interviewing. We were motivated to use the computer in medical histories because northern Wisconsin was short of physicians, and the need for assistance was apparent. For those physicians seeing 60 to 70 patients a day, medical history taking was a real dilemma. Frequently, they had barely enough time to ask "Where does it hurt?" — let alone all the other questions in a full interview. Medical history taking, and the medical interview in general in the United States, is a very time-consuming process. And as a corollary to this, it is very expensive. Talk is not cheap in medicine.

As you know, a number of self-administered questionnaires have been developed, the classic example being the Cornell Medical Index (1). Many good self-administered questionnaires are used throughout the country today. A problem of this type of questionnaire, however, is that it is difficult to individualize the process. If the patient says "yes" to the question, "Have you ever coughed up blood?" there may have been a speck from the nose 10 years ago or a massive hemoptysis yesterday. It is up to the clinician to ascertain the significance of this response. It is also difficult to provide help in the interaction. Patients may misunderstand the question. It is hard to explain an item. They may skip an item. They may lose a page of the questionnaire.

Beginnings of the Computer History

Having considered the various questionnaires in use and the dilemmas of the physician as an historian, we decided to embark upon our project with the computer. The idea was to incorporate some of the advantages of the physician as a history taker, namely the ability to qualify abnormalities in great detail and to individualize the process in an appropriate, dignified, and considerate dialogue with the patient. Simultaneously, we wanted to preserve the advantages of the questionnaire,

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namely its completeness and its economy of time and money.

We planned to standardize responses so that we could pool them later and learn more about the medical history as a tool. In spite of the obvious importance of the medical history, we are remarkably ignorant about its utility. If you ask the professor of neurology in the medical school to explain the importance of the question, "Do you have a headache problem?", I venture to say she or he cannot answer. We really know far less about medical-history items than we do about laboratory data, e.g. BUN, alkaline phosphatase, etc.

We decided to start with allergy for the first computerized interview (2). It seemed like a neutral area, and our allergist consultant, Charles Reed, gave his enthusiastic support. We did not want to start in psychology, and we certainly did not want to do mental testing; we would prefer to do in mental testing. We also thought an allergy interview would be short. When we finished there were over 1500 frames in the system, and we had to stop it from continuing to expand. We used a LINC computer invented by Wesley Clark and Charles Molnar at MIT (3). This was an extremely versatile machine built primarily for neurophysiologists in the early 1960's. It had a small cathode-ray tube on the console, was slow by today's standards, and there was a lot of flicker on the screen.

In the meantime, a number of colleagues expressed concern over our idea. Some people were saying it could not be done. Some felt it could be done but shouldn't be done, and others said patients would not permit themselves to be interviewed by a machine that was performing a function traditionally in the province of the physician.

To be perfectly frank, it took quite a while to get up the courage to try the first clinical interview. I went to the medical service of the University of Wisconsin Hospitals and asked an elderly gentleman if he would give me a hand with this experiment. I told him the general idea and that I didn't know how well it would work. He said he was willing to try anything once, and he walked with me to the computer in the Medical Sciences building. The man sat down and I dimmed the lights. The opening line came on the small screen in its eerie, flickering manner, reminding me of Kafka's Castle.

This gentleman got going at the keyboard, responding to the questions appropriately, and after a while it became clear that there was a rapport between him and the machine. He was laughing out loud at some of the things from the computer. Some I had intended to be funny; some I hadn't. He was saying things like, "That was a dumb question -- you already asked me that!" That was true, but I know that he never would have said that to me as a doctor with white coat and Bakelite nametag. The physician presents as an authoritarian figure. On the other hand, the patient was very comfortable with the machine and criticized it freely. At the end of this interview, he turned to me and said, "You know, doctor, I really like this computer better than those physicians upstairs." Surprised, I asked him why. He said, "Because I'm deaf and can't hear them anyway!"

With the notion of a computer taking a history, lots of thoughts come to mind -- "2001 Space Odyssey," thought control, "What's the world coming to?" "The computer is taking over," and so forth. But I think what happened with this patient was that, for the first time in his medical experience, he was in control; he was in charge of the interview. And, in his world of deafness, he could communicate well with the machine. We were lucky that our first patient had such a positive attitude.

After the interview was over, the teletype started to print a summary for the physician, converting some words like "hives" to "urticaria" and hay fever to "allergic rhinitis." Other than that, the print-out corresponded to what the patient had told the machine. The gentleman turned to me and said, "What's happening? May I read that?" I could not think of any reason why he shouldn't. This may have been one of the first times that a patient at the University of Wisconsin Hospitals was permitted to read his own record. As he started to read, he said, "No, that's wrong, I didn't mean that." And he picked up a number of errors. There was obviously some "noise" in the interview. And henceforth, we have asked our patients to help us edit the medical history. They have been very, very helpful over the years. For patients who want to participate in their own medical care, the medical record shoud be declassified as quickly as possible.

We were pleased with the results of the first history. We did a small, formal study with the allergy interview

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and found that the computer was reliable in asking questions, and found it picking up some information, such as allergy to penicillin, that had not been mentioned in the chart either by the medical students, interns or residents. We became generally comfortable with the process, and our experience has been that patients really like the computer interview very much. As a matter of fact, the thing that I am most confident about right now with regard to patient-computer interaction is that it is _fun_ for the patient. Furthermore, with the computer, the patient can be given control of the interview.

We now do our interviewing with time-sharing, with many terminals being operated by one computer. At Beth Israel Hospital in Boston, we use Data General's Eclipse C-330 computer and develop our programs in the MUMPS language (4). The basic concepts of "branching logic," which we originally developed for the computer history, are still used (5).

Branching Logic with the Computer

Let's consider a typical set of questions and answers. In response to the question, "Have you ever had hives?" if the patient presses "yes," the computer response will be, "Do you have any idea what caused your hives?" If the patient does not know or does not understand the question, the computer will explain the meaning of "hives" and then return the patient to the original question. If the patient has had hives, the computer branches to a set of questions about frequency, duration and severity and then goes on to the next question.

I had never seen a "don't understand" option on a printed questionnaire, perhaps because there was nothing that could be done about it. But the computer could branch to explanatory sequences in conjunction with "don't understand." Also, we could focus on questions that were consistently not understood and either reword them or eliminate them from the interview, because they were bad questions.

We have added to our original four responses (yes, no, don't know, don't understand), a fifth option: "skip it." The assumption is generally made that the patient should answer every one of the physician's questions. If the patient does not answer, she or he is a "bad patient." The patient is "recalcitrant." Philosophically, I am opposed to this notion. Patients should not have to answer questions if they don't want to. Early in our work

I used a "None of your damn business" option. We have since toned it down to "skip it," better accepted in Boston.

The Computer Dialogue

The dialogue between the computer and patient starts off: "Hello there. We are very much interested in helping you with your medical problems. First we would like briefly to show you how to operate the machine. Please find the 'go' key on the keyboard and press it." If the patient does that, the computer continues: "Excellent, you are doing fine. If you already know how to operate the machine you can skip the instructions by typing 'yes' and then the 'go' key; otherwise, just press 'go' and we will show you how things work."

What follows is a short teaching program. It has two purposes. It is similar to a brief mental-status evaluation, trying to find out if the patient is capable of operating the computer terminal. We know at the end of this teaching section that the patient is alert, can read the frames on the screen, is capable of sustained mental activity and is ready for the first medical question. If the patient can learn our program, the likelihood that she or he will be imparting meaningful information to the computer is high. There are 10 or 12 small companies that now market computer histories, and some have built boxes that make it very easy for the patient to answer, being concerned that a standard keyboard would be too difficult. However, the keyboard is not too difficult in our experience, and it is the least expensive method of communication with the computer.

The program continues: "Please type your first name." Although we do use open-ended entries like this, most of the questions have a multiple-choice format because this is the easiest for the patient to handle. "May we call you by your first name?" If yes, the computer will call the patient by name and remember age and sex and other appropriate information. Also, we are now using follow-up interviews so that the computer can look back to problems mentioned in previous encounters and incorporate this information into the current interview.

Computer Instruction

The computer can teach the meaning of words and qustions that are not understood, like "hives" or "electrocardiogram." It occurred to me that _we_ were learning a lot about a person during a computer interview, and

that we might be able to turn the situation around and offer patients information that would be of help to them and relevant to their problems and help them to gain control of the clinical process.

My first attempt was an instructional sequence dealing with allergy (6). At the end of the section on hay fever the computer asked, "Would you like to know something more about it?" Practically everybody said yes, they would. The machine then took them through a course designed to teach about hay fever: where the various allergens are found and how to avoid them. This was quite popular in our early experience. It made me excited about the potential of the computer to help the patient directly. The patient as a consumer wants information about health care. Magazines at check-out counters always have at least one article on how to care for this or that, yet it is very difficult for a patient to gain enlightenment from professionals about self-care.

I think there is a great potential for the interactive computer as a counselor and a guide to patients. Eventually, there may even be interactive televisions within people's homes. Certainly it would be a lot better than the one-way televison that now pervades our living rooms. As a matter of fact, I think that writing interactively will become a new art form. It is unlike other types of writing. It is a new dimension in writing. None of us knows how to do it very well as yet.

Nutritional Counseling

We have done some research with computer instruction for patients with urinary tract infections (6). Another area where we thought we could help patients was in nutritional counseling. Perhaps we could use the commputer to obtain a detailed dietary history and then provide useful information to the patient, helping plan a diet, e.g., a weight-reduction diet in the range of 1500 calories. The program was written in collaboration with Jelia Witschi and her colleagues in Nutrition at the Harvard School of Public Health and evaluated by Douglas Porter and colleagues within our Computer Medicine Laboratory at the Beth Israel Hospital. It consists of three parts (8). The first is a general dietary interview: the second is what we call the usual day interview, where the computer asks what the patient generally eats in a typical day — the first meal, the snacks, lunch, afternoon snacks, evening and late night eating. The

third part consists of a diet planner, where likes and dislikes are taken into consideration and the computer, with the patient in control, helps develop a weight-reduction diet. Summaries are then printed for patients and nutritionists. These include a detailed list of the calories of the food eaten on a usual day. In a study with this program, nutritionists were found to spend less time with their own interviews if the patients had seen the computer first. The nutritionists found the program helpful (9).

The comments of the patients were sometimes striking: people said things like, "The computer was an extension of myself:" "It really got me to thinking about what I am doing to myself." The dialogue with the machine seemed to help with the process of self-reflection. Dialogue with a computer is, after all, dialogue with oneself.

Psychological Counseling

I would like to mention very briefly one other experiment. My brother, Charles, and I have developed the hypothesis that talking out loud and alone can be therapeutic. We can't prove that it works, but if it does, the price is right. We did one experiment with the computer to test this (10). Speech-understanding systems by machine are not yet with us. There is work at the Bell Labs and at Carnegie Tech to develop machines able to understand freely-spoken words, but a good working system is a long way in the future. Our idea, very simply, was that we did not need to have the computer understand what people were saying. We did not want it to understand. We wanted people, in essence, to be talking to themselves, working things out on their own, with the computer as a facilitator of soliloquy.

We programmed a PDP-12 computer in our lab with a brief psychological history of 10 questions — Have you been feeling sad or down in the dumps? Have you been having trouble with your parents? Are you a student in Boston? Have you been having any trouble with school? Are you having trouble with drugs? etc. Then the computer wrote on the screen, for example, "You've indicated to us that you've been feeling sad or down in the dumps. Would you be willing to talk a bit about this?" And if the person pressed "yes," the computer would say, "Fine, tell us about your sadness." The microphone in front of the machine was connected to the computer so that it could sense whether the person was talking or not, though it could not

"understand" what was being said. We programmed some timing arrangements: for example, if the patient said nothing for 20 seconds, the computer replied with, "Are you having trouble getting started?" If the "yes" key was pressed, the computer suggested, "Well, begin by saying — 'My sadness seems to stem from' ..." This seemed to help people get started. Later in the program, the computer presented statements that encouraged discussion about personal feelings on the mind of the respondent at the moment: something about the respondent that could not possibly be true: a personal problem considered in a very rational way: and an example of behavior that, in the respondent's opinion, was a "responsible act" — topics considered important to the psychology of Freud, Ellis Glasser and Rogers. Discussion was acknowledged with words such as "We are 'listening' to you talk about ... If finished, press 'GO.'" Once again, delays in getting started and prolonged pauses during discussion resulted in words of explanation and encouragement. A person could refuse to discuss anything suggested by the computer and could leave a topic at any time.

Thirty-two young volunteers came and talked at great length to the computer. Some felt they had been helped by talking things out. We were encouraged by the results and plan further research of this type (11).

Conclusion

Much research remains to be done, but we are optimistic about the potential of patient-computer dialogue to help patients care for themselves when confronted with medical problems and to assume control of the clinical process — to make their own medical decisions based on good information — when they are comfortable in doing so (12).

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